

Fibromyalgia:

An opportunity to explore the human experience of disability, and the implications for rehabilitation

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Fibromyalgia (FMS) is one of the most common musculoskeletal conditions identified in all industrialised countries.¹ The most dominant features of FMS are generalised muscle pain and fatigue.² Other symptoms include: stiffness, sleep disturbance, headache, bowel and bladder dysfunction, anxiety and depression.³ More objective findings, for the purpose of diagnosis, have been identified by The American College of Rheumatologists in the 1990 Criteria for the Classification of Fibromyalgia.² The criteria are: firstly a history of widespread pain and secondly pain in 11 of 18 sites on digital palpation. FMS can also be diagnosed as a secondary condition to other musculoskeletal diseases, such as rheumatoid arthritis, osteoarthritis and post-polio syndrome.⁴

FMS, originally known as fibrositis,⁵ is thought to affect 2% of the adult population.^{1,6} Goldenberg estimates that there are between three and six million people with the condition in the United States. It is thought to affect 10 times more women than men, with 3.9% of women aged 20–40 and 5.8% of women aged 40–60 having a positive diagnosis.¹ Rheumatologists estimate that approximately 20% of referrals are due to FMS,⁵ with other specialists reporting similar figures.⁸ FMS is also prevalent in the workplace with 25% of people with FMS receiving some form of disability or injury compensation.¹ Littlejohn has argued that an epidemic of FMS occurred in the workplaces of Australia

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in the 1980s, with some 30% of public service workers being affected.⁹

Many theories regarding the exact cause of FMS have been presented, ranging from neurobiological explanations to the impact of psychosocial factors, particularly stress. Entire publications, such as *The Rheumatic Disease Clinics of North America*¹⁰ and *Bailliere's Clinical Rheumatology*¹¹ have been devoted to the debate, but no organic impairment has been identified. However, it is widely accepted that FMS is a multi-factorial illness with a wide range of symptoms, which constitute a syndrome.² With the cause remaining unclear, FMS has become one of the most controversial health problems of our time.⁷ However, people with FMS and health professionals alike seem to agree that the pain of FMS has the potential to 'convert otherwise healthy persons into invalids'.¹²

The multi-dimensional features of FMS creates a cycle of on-going pain and stress that leads to 'impaired mental and physical performance'. In addition, when caught in this cycle indi-

viduals are unable to function and experience fewer supportive social interactions.¹³ Chapman and Gavrin argue that the inability to function as one feels one should is a threat to 'self' and ultimately results in 'suffering'.¹³ If disability is defined as 'a limitation of function that compromises an individual's ability to perform an activity within the range considered normal'⁶ then this is the disability of FMS. Bennett comments on several studies indicating that those with FMS are equally limited in their capacity to work, and have similar scores on disability scales to those diagnosed with rheumatoid arthritis and ankylosing spondylitis.⁶

Those experiencing this kind of disability will present to the medical profession for diagnosis, treatment and cure.³ As is appropriate, the medical model will be applied in order to find the impairment and cure the problem. Other health professionals may be called in to provide treatment, with the goal of reducing pain and increasing function. The 'patient' is a passive recipient, whose only re-

sponsibility is to comply.^{13,15} Those with FMS have discovered that this approach can mean years of treatment with little or no improvement.¹⁶

More recently, programmes offered utilise a more clinical model. The difference between this and the traditional medical model is that this approach is more client driven.¹⁷ Services are still offered by multi-disciplinary teams, from hospital settings, but the model of rehabilitation is now more compensatory.¹⁵ Individuals are seen as being responsible for solutions, even if they are not responsible for the creation of their problem. The focus is on Personal Adjustment Rehabilitation, being the '*restoration of confidence and independence enjoyed before the onset of a disability*'.¹⁷ The goals of reducing pain and increasing function are still important, as in the medical approach, but they are now worked on through a process of self-management. This includes self-regulation (increase in self-efficacy and coping) often utilising the cognitive-behavioural strategies and physical exercise training (increase fitness, strength and endurance) promoting the establishment of an on-going home fitness programme.¹⁸

Generally, programmes include services offered by a physician (predominantly rheumatologists or rehabilitation specialists), nurse, physiotherapist, occupational therapist, psychologist, social worker, counsellor, balneotherapist, hypnotherapist, acupuncturist and whoever else may be available to offer assistance. The role of any of the professionals in the self-management process is to '*serve as trainers and provide education about FMS and guided instruction in specific self-management strategies*'.¹⁸ The way this is actually performed is now a matter for debate.

Potts and Silverman have indicated that satisfaction with programmes can be low if there are differences between the views of the physician and the person with FMS. Non-compliance is a

term often used and those with FMS may be labelled as: '*hysterical, hypochondriacal, or malingering*'.¹⁹

As a result of this kind of outcome, and with no impairment being identified, the response to the condition can become quite dismissive.^{6,20,21} A qualitative study exploring patients' understanding of the meaning of their illness, found that '*the patients were intensively involved in efforts to get their self-images as ill-persons confirmed*'.²² Hadler also discussed this issue, and said it all in his paper *If you have to prove you are ill, you can't get well*.²³

Commonly, this perception is attributed to '*western medicine's dualistic ontology*'²⁴ that leads to the assumption that if there is no impairment then the condition is all in the mind. Others perceive FMS as the individual '*excessively exaggerating*' or '*putting it on*'.¹⁶ Alternatively, the search for an organic cause may be relentless involving expensive and invasive tests, even surgery, with often further debilitating consequences.⁴

Without an understanding of the whole person, those with FMS can, and often are, misjudged, misdiagnosed and mistreated, or denied access to treatment and support that may be beneficial. This may result in a handicap for those with FMS. If the goal of rehabilitation is to 're-enable' or 'restore', then a truly holistic approach may be more effective.

In response to this, other models have been presented that are more holistic. McIndoe and Littlejohn have developed a Mind-Body Model that explains how all the factors interact.¹⁶ McIndoe believes that the use of this model recognises that '*physical treatment alone is not enough (and that) the person's beliefs about the pain are crucial*'.²⁵ As an extension of this he has also developed a Self-Management Model, which is similar to the

Armentrout Wellness Model¹⁴ and focuses on positive aspects, that is on an individual's strengths, shared responsibility and the spiritual factors important to the person.

For this to be successful the relationship between the person with FMS and the health professional needs to change. In the medical model this relationship is essentially a parent-child

one. For self-management to be successful, it is suggested that an adult-adult relationship is more appropriate.²⁶ Anderson makes sound arguments for this, presenting a Patient-Empowerment

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Model based on recommendations that fit well with the philosophy of rehabilitation. These include that the locus of control and decision-making rests with the person, that the health professional's role is to provide ongoing expertise and information so that the individual can make informed choices, that the use of pejorative terms is discontinued, that medical schools include interpersonal skills training to equip health professionals for this role and that this relationship is established through discussion, with the clarification of roles and responsibilities. Within this environment an individual's 'story' can be shared and understood, allowing for better assessment, planning and treatment provision. It also allows for the acknowledgement of the difference between pain and suffering.¹³

At the New Zealand Pain Society Annual Scientific Meeting in 1999, the author presented a character called FRED (Feel Rotten Every Day) who symbolises 'suffering'. FRED is a product of the stress/pain cycle that often leads to the development of negative coping and ultimately disability. This experience is seen as a normal human response to adversity, and provides the opportunity for unique personal growth.²⁷ With greater understanding of this experience an individual can work towards self-growth and empowerment, becoming no longer disabled.²⁸

FMS has become one of the most controversial health problems of our time

Masi provides a summation of these factors.³ He presents an Intuitive Person-Centred Systems Model. This approach is said to '*assist and support the person in assuming major management responsibility for the control of pain, improved function and general self-rehabilitation*'. The focus is on individualised determinants for rehabilitation, with a greater awareness of FRED. In addition, it is recognised that it is the beliefs and behaviours of health professionals that need to be challenged for this to work. It is only by seeing 'patients' as people that an understanding of their 'suffering' can be reached. The responsibility of the health professional is to restore freedom of choice rather than make choices for our patients.

The growing body of self-help literature written by those with FMS,

promoting ways of coping without professional help, would indicate that there is dissatisfaction with some of the services currently offered. Health professionals would do well to review their approach to this condition and consider the models and philosophies that are now emerging. If this does not happen, those with FMS could find themselves at the other end of the rehabilitation continuum, and in Independent Living Mode. Whilst this would mean that those with this condition would be totally responsible for determining the approach to FMS (compensatory model), and even work on removing societal barriers which would be an advantage, there may also be a cost. It has been argued that when the compensatory model is utilised to this extreme, there is a risk of developing a 'nega-

tive or paranoid view of the world'.¹⁵ In addition, this type of behaviour is often associated with type 'A' personalities, that is predominantly perfectionist, controlling and competitive.¹⁵ Some would argue that these two factors contribute to the development of FMS in the first place.^{29,30} In summary, FMS is a controversial condition. The lack of identified impairment, but the existence of a very real disability, has challenged many longstanding beliefs about health. The opportunities that have been presented and lessons learnt have provided valuable insights into the experience of FMS. These may also be useful for understanding the human experience of other chronic, disabling conditions. Perhaps this knowledge will lead to an evolution of rehabilitation practice.

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